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# Stress in professional care-givers working with patients with dementia: a hypothesis-generating study

Original Citation:		
Availability:		
This version is available http://hdl.handle.net/2318/98587	since 2018	-10-16T10:33:34Z
Published version:		
DOI:10.3275/7412		
Terms of use:		
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# STRESS IN PROFESSIONAL CAREGIVERS WORKING WITH PATIENTS WITH

## **DEMENTIA: AN HYPOTHESIS-GENERATING STUDY**

Running head: stress in nurses working with patients affected by dementia

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Key words: Nursing Education, Nursing Practice, Dementia Care, Nursing Homes, Stress

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Received July 29, 2010; Accepted in revised form November 30, 2010.

Abstract

Background and Aims. Care giving can be extremely stressful, especially when the patients' ability

to communicate is impaired. While the stress of relatives assisting their beloved ones has been

largely investigated, fewer data can be found about the stress in health care professionals. The aim

of this study is to evaluate whether a specific training course could be related to a reduction of the

levels of stress of professional caregivers working with patients suffering from dementia.

Methods. Work-related levels of stress of study participants were evaluated with the Staff Stress

Measure Dementia Care Scale, at baseline and four months after completion of an eight-month

training course.

Results. We found no significant correlation between caregivers' age, gender, marital status, years

of employment and perceived economic status and their levels stress at baseline. Characteristics of

the patients were not related with caregivers' stress at baseline. The mean level of stress was

significantly reduced (34.64±4.15 vs 26.64±3.82, p<0.001) between baseline and study end point.

Conclusions. An increased knowledge of management of patients affected by dementia could help

professional caregivers in reducing their work-related stress. Our results seem to add to the

evidence of a benefit of personnel support in reducing the levels of stress at work.

Key words: Nursing Education, Nursing Practice, Dementia Care, Nursing Homes, Stress

## Introduction

In developed countries, the number of older people needing health and long-term care is increasing. Functionally and cognitively impaired older people put a heavy burden on the health care workers. Nursing staff in residential-aged care settings have a difficult and challenging job (1). People employed in nursing homes and long-term facilities work long hours, are poorly paid, receive minimal benefits, while the patients they care for present an elevated burden of care. Care giving can be extremely stressful, especially when the patients' ability to communicate is impaired (2). Novak and Chappell observed that the worse the cognitive impairment of the residents, the more severe the level of stress of the health care professionals caring for them (3). At the same time, several studies have reported that heavier work loads have led to increased time pressure among nursing staff, resulting in higher levels of stress (4, 5).

Health care professionals have been found to respond to their inadequacy not only with tension, anxiety and avoidance, but also with decreased self-esteem and job satisfaction. This can lead to depression or burnout, determining what is usually known as "work-related stress".

Stress has been defined as a subjective psycho physiological state characterized by a combination of high arousal and displeasure (6). It is considered to result from an imbalance between the demands of the workplace and an individual's ability to cope.

Stress often results in adverse physiological and psychological outcomes for both caregivers and recipients (7, 8) and high job strain is associated with increased risk of a multitude of illnesses among workers (9, 10).

While the stress of relatives assisting their beloved ones has been largely investigated (11, 12, 13), fewer data can be found about the stress in health care professionals, with the exception of personnel working with cancer patients (14).

During the last few decades, some educational programs, aiming to reduce the stress of professional caregivers, have been developed. Although the reduction of the length of shifts and of the number of patients each health care worker must take care of would probably be effective in ameliorating

the quality of work life, these goals are hardly achievable in health care systems with limited economical resources. Training courses, based on cognitive, emotional and behavioural approaches, on the other hand, are more feasible and could help reducing the professional caregivers' stress by providing them with better knowledge and more realistic expectations.

Main aims were to identify which items of a specific staff stress scale are mainly compromised in professional caregivers and which items are mainly modified after a specific training course, aimed to improve knowledge in management of patients affected by dementia. Moreover, the study aims to highlight the problem of burden of professional caregivers in long-term facilities by reporting the main features of patients they have to care and by researching possible relationships between stress and patients' characteristics.

## Methods

The study has been performed in two nursing homes, located in Torino, northern Italy. The two nursing homes belong to the Department of Geriatrics of the city University Hospital and host 200 non-independent older subjects. All the registered nurses and nurse assistants working in the two facilities were asked to participate to the present study.

Data on gender, age, marital status, and years of employment and perceived economic status of the professional caregivers were collected. Data on gender, age, marital status, and years of employment, perceived economic status and levels of stress were collected for non-participating nurses as well.

All participants underwent a baseline evaluation of their level of stress using the Staff Stress Measure Dementia Care (15), a scale specifically designed and validated for health care professionals working with patients affected by Alzheimer's disease or similar degenerative mental conditions. This scale is composed of 20 items; each item presents five possible answers: 0=never, 1=a little, 2=sometimes, 3=often and 4=always. The score is calculated by the sum of these items, higher scores indicating higher levels of work-related stress.

All study participants underwent a training course designed to increase their knowledge about the care of older, cognitively and functionally impaired subjects and to enhance their capability to cope with stress-generating situations. The course lasted eight months, from January until August 2006, and consisted of two hours of training per week for a total of 32 hours of theoretical lessons and 32 hours of role playing exercises and experiential exchanges. The main topics of the theoretical lessons were as follows: aging and cognitive impairment, symptoms and stages of dementia, management of behavioural and psychological symptoms related to cognitive impairment, nutritional issues in the patient affected by dementia, pain evaluation and control in patient suffering from dementia, strategies for a successful communication with the patient with dementia, impact of dementia on the quality of life of the caregiver, psychosocial and ethical issues associated with dementia and the continuity of care. In each lesson, the specific topic was developed with

attention to the stress related aspects and the possible interventions that could be used in order to reduce the work stress. Theoretical lessons were completed by the presentation and discussion of clinical cases and the projection of video clips. At the end of each lesson the participants were given a paper with a summary of the discussed issues and some review questions. A total of 16 role playing exercises were scheduled. For the role playing exercises, participants were divided into five groups of ten people. During every practical lesson, each group role-played one scenario. Each scenario was presented by two participants with the help of the teacher and with an actor playing the role of the patient. After the first 10 scenarios, the actor was substituted with a patient affected by dementia. Scenarios aimed to put the topics presented during theoretical lessons into practice. The training course was held by a senior physician working at the memory clinic of the Department of Geriatrics of a university teaching hospital (San Giovanni Battista, Torino, Italy), by a nurse with expertise in the care of patients suffering from dementia, and by a psychologist skilled in group training and role playing. Two theoretical lessons (nutritional issues and pain evaluation and control) were given by nutrition and pain specialist, respectively. Table 1 reports the essential

At the end of each lesson every participant could ask their teachers some questions on the specific lesson they attended or on other topics they experienced during the past lessons or during their daily work. Moreover, the nurse and the physician holding the training course dedicated to the students one hour per week, between the end of the course and the follow-up evaluation, in order to answer possible questions and giving a work-support in general.

characteristics of the course.

One year after the baseline evaluation, professional caregivers underwent the same evaluation of stress that they did at baseline. Each item of the Staff Stress Measure Dementia Care measured at the end of the study was compared with the same item measured at baseline.

Data on patients' characteristics (age, gender, grade of cognitive impairment, functional status, entity and frequency of behavioural disturbances) were also collected.

The Clinical Dementia Rating Scale (CDR) was used to evaluate the degree of cognitive impairment. It is a five-point scale with CDR-0 indicating no cognitive impairment, and with the remaining four scores indicating progressively more severe stages of dementia (CDR-0 = absent, CDR-0.5 = very mild, CDR-1 = mild, CDR-2 = moderate, CDR-3 = severe) (16, 17). The Activity of Daily Living Scale (ADL) was used to evaluate the functional status of the patients. The Cohen–Mansfield Agitation Inventory (CMAI) was used to estimate behavioural disturbances. It is a 29-item questionnaire specific for patients with dementia that have to be completed by a formal caregiver (18) and that define agitation with a 7 point frequency scale (0 = never and 6= several times per hour).

All data were collected by a geriatrician, with more than 5 years of experience in geriatric research, who was not aware of the objective of the study and who had no role either in the study analyses or in the care of patients. Informed consent for study participation was obtained from each professional caregiver and from each patient or proxy (closest relative or legal tutor). The study was approved by the Ethical Committee of our Hospital.

## Statistical analysis

Statistical analysis has been performed using SPSS 15.0 packaging for Windows. A descriptive analysis of continuous and categorical variables was performed. The Independent-Samples t test procedure was used to evaluate differences in mean values between groups. The Paired-Samples t test procedure was used to evaluate differences between baseline and follow-up. The p<0.05 indicates statistical significance. The effect size between pre- and post-training Staff Stress Measure Dementia Care scale score was measured using Cohen's d (with 95% confidence interval). ANOVA was also used to evaluate differences in Staff Stress Measure Dementia Care scale score between baselines and follow up.

Data are presented as mean  $\pm$  SD (95% confidence intervals) or as percentages in the corresponding categories.

## **Results**

Fifty professional caregivers participated to the present study. Twenty seven of the 40 professional caregivers employed in the first nursing home and 23 of the 40 professional caregivers employed in the second one accepted to participate to the study. Of the thirty health care workers who did not participate 28 were not interested in the study and two dropped out of the study before its end. Mean age of the workers enrolled was  $42.9 \pm 8.7$  years (range 25-63), 42 (84%) were female, 32 (64%) were married, 10 (20%) unmarried, 1 (2%) was widow and 7 (14%) were divorced. They had worked in the facility for  $13.6 \pm 10.0$  years (range 3-35 years). Salaries were considered insufficient by 62% subjects in the study. The Staff Stress Measure Dementia Care Scale scores, indicating the professional caregivers' levels of stress, were  $34.6 \pm 4.1$  and  $26.6 \pm 3.8$ , at baseline and after one year of follow-up, respectively (t = 10.03, p<0.001; Cohen's d effect size = 1.93, confidence interval 95% 1.44 - 2.39). Table 2 shows mean values of the single items in the Staff Stress Measure Dementia Care Scale at baseline and after one year of follow-up.

Thirty (37.5%) of the 80 nurses working in the two nursing homes did not accept to participate to the study. This could reflect the difficulty in obtaining a good adherence to educational courses in real life settings. However, no significant differences were observed between participating and non-participating nurses as to age (t = 1.67, p = ns), gender (Chi-Square = 3.30, p = ns), marital status (Chi-Square = 2.09, p = ns), years of employment (t = 2.89, p = ns), perceived economic status (Chi-Square = 2.77, p = ns) and level of work-related stress (t = 0.97, t = ns).

The patients assisted in the two nursing homes at the beginning of the study time period were 212; their mean age was  $81.7 \pm 8.7$  years (range 62-99 years); 132 (62%) were female; their mean CDR was  $2.5 \pm 0.5$ , (97% classified as CDR-2 or CDR-3); their mean ADL was  $5 \pm 1.2$ ; their mean CMAI was  $21.9 \pm 19.2$ .

We did not find significant correlations between the caregivers' levels of stress (Staff Stress Measure Dementia Care score) and their age (r = -0.28, p = ns), gender (Chi-Square = 2.08, p = ns),

marital status (Chi-Square = 4.02, p = ns) and perceived payment (Chi-Square = 3.18, p = ns), at baseline.

Neither functional nor cognitive status of the patients were related to the caregivers' levels of stress at baseline (r = -0.17, p = ns and r = -0.26, p = ns respectively). Moreover, the behavioural disturbances were not statistically related to the caregiver stress (r = 0.61, p = 0.672).

Although no correlations between work-related levels of stress and caregivers' characteristics were observed at baseline, the effect of possible confounders was evaluated by ANOVA: the decrease in the levels of work-related stress at one year remained statistically significant after forcing age, gender, marital status, years of employment and perceived economic status in the model (F = 12.67, p < 0.001).

The items of the Staff Stress Measure Dementia Care Scale that had shown the highest scores at baseline showed the most consistent improvements at one year of follow-up [items number 9 (I really get tired working with these residents), number 4 (I get tired of repeating things to them so much), number 8 (I get mad when they deny problems and blame others for things), number 7 (It is very hard for me to communicate with these people), number 11 (I get frustrated and angry working with these people)]. Only item number 16 (It worries me these people will wander off) showed a higher score after one year than at baseline.

After one year of follow-up, the items with the highest scores were item number 16, item number 5 (their families just do not appreciate what we do for these people), item 17 (I feel it takes too long to do things for them) and item 19 (I believe we should have more training to work with them). On the other side, the items with the lowest score were item number 8, item number 15 (I feel these residents should appreciate our help more) and item number 14 (I take my work with them home with me).

#### **Discussion**

The present study evaluated the levels of work-related-stress of professional caregivers working in two nursing homes before and after having participated to a training course targeted to the management of older, cognitively impaired patients.

Working with patients affected by dementia has been shown to be very stressful (2, 3): affected subjects can be aggressive or listless and it could be difficult to create a relationship, caring might evoke feelings of meaninglessness (19) and, in particular situations, such as in case of disruptive behaviour, the caregiver could feel insufficient (20).

Our results cannot relate stress to anyone of the outcomes described. The levels of stress of professional caregivers do not correlate with the patients' degree of cognitive or functional impairment, or with the frequency of behavioural disturbances among the assisted subjects. Moreover, age, gender, marital status and perceived economic status of the caregivers do not influence their levels of stress.

A possible explanation could be that we have not accounted for other variables possibly involved in the stress' generation, and this could be a limit of the study, however most important variables have been collected. Another possible explanation could be that staff stress is mainly caused by the individual perception that professional caregivers have on their patients. A critical interpretation of our results suggests levels of stress at baseline being related to a lack of understanding of the typical features and needs of patients affected by dementia: after the training course not only global stress was reduced but, the reasonable fear of the patients wandering off (item 16) took the place of the frustration deriving from communication difficulties (items 4, 7 and 8) on the top of the nurses' worries. Moreover, it is important to underline that the CMAI scale did not show high results, describing a population without relevant behavioural problems. It could be possible that performing a study on a higher number of patients could produce different results.

It is relevant to underline that the course was not specifically structured to obtain a better performance to the stress test. The fact that professional caregiver stress was not related to several

variables evaluated, allowed us to hypothesize a possible role of the individual perceptions and knowledge. However, the weak design of the present study and the low number of participants do not allow drawing strong conclusions.

Some studies (21, 22) have described strategies for the management of stress, often focusing on specific illnesses. These interventions are usually divided in personnel support interventions, aiming to teach the personnel how to best deal with a variety of stressful situations, and environmental management interventions, aiming to reduce the sources of stress on the work place. As reported by Mimura et al (23), more evidence is available for the effectiveness of personnel support than of environmental management. Lack of support can be either a stressor or an effective coping strategy depending on its presence or absence. The lack of managerial support and direct leadership for staff induces stress. A supervision aimed to implement individualized planned care has shown to decrease incidence of burnout and to increase job satisfaction among samples of nurses (24, 25). On the contrary, other authors (26, 27) reported that the lack of support at work did not contribute significantly to nurses' levels of stress.

The field of educational interventions for nurses and professional caregivers is expanding. However, programs uniquely based on lectures are often seen as boring by recipients. The review of the literature gives no indication why role playing would be effective in achieving the desired outcomes, but, in our opinion, the opportunity of alternating theoretical lessons and role-playing could be more appealing and more effective, producing better learning results.

The results of the present hypothesis-generating study suggest that an educational course consisting in both theoretical lessons and practical training sessions are effective in reducing the personnel's level of work-related stress, in a sample of nurses dealing with cognitively and functionally impaired older patients.

Our results are partially in contrast with the findings of other Authors who identified excessive work load, long duty hours, financial problems, conflict between professional and personal life and the feeling of responsibility for patients' outcomes among the main determinants of stress (28, 29,

30). These differences could be explained in different ways. First, previous studies were conducted on samples of health professionals working with cancer patients rather than with subjects suffering from dementia. We could speculate that a formative course is more likely to help professional caregivers coping with issues in communication with a patient with dementia than with the lack of hope of terminal cancer patients. Second, the other studies used other tools to measure work-related stress. We chose to use the Staff Stress Measure Dementia Care Scale because it has been specifically designed for measuring the stress of health care workers dealing with patients affected by Alzheimer's disease, in nursing homes and day care centres.

A possible objection to the present study could be advanced by looking the relatively low Staff Stress Measure Dementia Care scale score. The relatively low score (34.6 points) would not prompt a training course for the nurses. However, many items report a mean score over 2 points meaning "frequently". In particular, some of these items, such as "I get tired of repeating things to them so much", "I get mad when they deny problems and blame others for things" and "I feel these residents should appreciate our help more" evidence a lack of knowledge in the management of patients with dementia. The same consideration could be done for the item "It worries me these people will wander off", whose score was low at baseline and increased after the course. The hypothesized lack of knowledge on management of these patients was the starting point of the course development. In fact, the course was structured in order to give a better knowledge on management and most relevant features of patients affected by dementia. The aim of the course was not to reduce caregiver's stress directly, but to improve knowledge in order to obtain a stress reduction. In fact, we did not mentioned self-controlling strategies, escape-avoidance strategies or social support as reported in other studies (31). The lack of these topics could be considered a limit in a reducing stress study, but not in a hypothesis generating study aimed to improve knowledge and, secondarily, to reduce stress. Although the weak study design, our results suggest that the lack of awareness could be involved in the work related stress.

To support the hypothesis of our study, several manuscripts have been published on the role of improving knowledge by practice (32, 33). Literature shows that an experiential approach is an effective strategy for teaching students and nurses (34). The uniqueness of this intervention would be the combination of experiences, ie role playing and lectures, and probably also the length of the intervention (8 months). It could be argued that the possibility of having a long-time disposition of special professional figures able to answer specific questions could be more efficacious than a shorter course.

Our study presents some important limitations. Because of the relatively small sample size our study should be regarded to as a hypothesis-generating one. However, the complexity of the proposed intervention makes it hard to recruit very large samples of subjects. Another critical aspect of our work is represented by the level of nurses' compliance to the course. We did not perform a specific evaluation of this topic, but the course was facultative, without any obligation and without any advantage for their vocation. Moreover, each participant could withdraw from the course without any consequence. The fact that only two participants interrupted to follow practical and theoretical lessons, could reflect a high level of compliance although it remains a limit for the study. More, we did not compare the effectiveness of one intervention with another intervention or with "usual care". This could make telling what really decreased the levels of stress more difficult. However, the long time nurses had worked in the two nursing facilities makes it very unlikely that levels of stress would decrease as a result of the personnel gaining experience. A follow-up of one year could be too short to evaluate if the effects of the course are permanent or at least long lasting. Finally, the different educational systems for nurses in different countries could make generalization of our results difficult.

## **Conclusions**

In conclusion, our results add to the evidence of a benefit of personnel support in reducing the levels of work-related stress. It could happen that nurses working with patients affected by dementia have not a specific scholar education in this field. Sometimes they learn their work during their practice, but some peculiarities of patients affected by dementia, in our opinion, require specific attention and teaching. The nurse reaction against some not-well known aspects of Dementia could be higher than expected and it could determine stressing emotions. This does not mean that nurses fail during their work, but it could let to hypothesise that a better knowledge could help professional caregivers in their work. This goal could have positive effects on patients too.

The limitations inherent to our study do not allow drawing definitive recommendations on a specific approach to improve working conditions and to reduce health care workers' stress. Further research, on larger samples of professional caregivers and comparing different interventions, is needed.

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Table 1. Schedule of the course

		Duration	
Aging and cognitive impairment		4 hours	
Symptoms and stages of dementia		4 hours	
Management of behavioural and		4 hours	
psychological symptoms related	clips		
to cognitive impairment	[] C		
Nutritional issues in the patient	video	4 hours	
affected by dementia			
Pain evaluation and control in	and/or	4 hours	16 role playing exercises
patient suffering from dementia	anc		of 2 hour each one
Strategies for a successful		4 hours	10 participants per group
communication with the patient	cases		
with dementia			
Impact of dementia on the quality	Clinical	4 hours	
of life of the caregiver	Cli		
Psychosocial and ethical issues		4 hours	
associated with dementia and the			
continuity of care			

Table 2. Mean values of the items in the Staff Stress Measure Dementia Care Scale at baseline and at one year of follow-up.

	Baseline	One year	
		follow-up	
Items	Mean±SD	Mean±SD	p-value
1. Their forgetfulness really gets on my nerves	1.26±1.27	1.1±1.18	ns
2. I believe these residents should do more for themselves	1.90±1.42	1.26±0.80	0.007
3. I am afraid these residents will get violent and hurt someone	1.34±1.56	1.42±1.18	ns
4. I get tired of repeating things to them so much	2.50±1.42	1.36±1.17	< 0.001
5. Their families just do not appreciate what we do for these			
people	1.68±1.62	1.9±1.18	ns
6. Their babbling and rambling speech gets on my nerves	1.96±1.37	1±0.95	< 0.001
7. It is very hard for me to communicate with these people	2.30±1.20	1.2±0.97	< 0.001
8. I get mad when they deny problems and blame others for			
things	$2.34\pm1.62$	$0.94\pm0.97$	< 0.001
9. I really get tired working with these residents	2.56±1.18	1.62±1.10	< 0.001
10. It is hard to accept what is happening to these residents	1.74±1.26	1.44±0.99	ns
11. I get frustrated and angry working with these people	2.24±1.42	1.25±0.93	< 0.001
12. I think more medication would make it easier to help them	1.16±1.33	1.28±1.21	ns
13. I have trouble talking to their families	0.90±1.31	1.18±1.08	ns
14. I take my work with them home with me	0.80±1.16	0.76±0.98	ns
15. I feel these residents should appreciate our help more	2.20±1.56	0.82±0.90	< 0.001
16. It worries me these people will wander off	0.96±1.26	1.94±1.30	< 0.001
17. I feel it takes too long to do things for them	1.90±1.37	1.66±1.15	0.06
18. It bothers me how helpless these residents become	2.14±1.47	1.46±1.05	0.005
19. I believe we should have more training to work with them	1.42±1.44	1.66±1.22	ns
20. It is difficult to explain their behaviour to other residents or	_		
families	1.32±1.56	1.4±1.07	ns

SD: standard deviation; ns: non significant